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ABSTRACT

This study examined the use of community resources and supports outside of formal infant/toddler and preschool programs for children with disabilities participating in early intervention programs in nine communities in three states (Colorado, North Carolina, and Pennsylvania). Data on community resource utilization were gathered for 16 months from parents of 135 infants/toddlers and 148 preschool children. Resources included child care, child therapy services, family need and support programs, health/mental health programs, recreational/socialization programs, and parent employment/education programs. Findings indicated that: (1) most families used community resources at least once during the period; (2) the proportion of families using resources increased over time; (3) child care services were the most frequently utilized resource; (4) the use of informal systems (family member or friend) was more prevalent than the use of formal systems; (5) approximately 34 percent of infants/toddlers and 39 percent of preschoolers received additional child therapy services; and (6) the use of child-centered services exceeded the use of family-centered services. Significant variability across communities was observed, suggesting that the community exerts a significant influence on the availability and utilization of child and family resources. The study protocol is appended. (Contains 24 references.) (DB)

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Early Childhood Research Institute on Service Utilization

Beyond Early Intervention: Utilization of Community Resources and Supports by Families with Young Children with Disabilities

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An Institute for the Study of Education, Health Care, & Social Service Utilization of Infants, Preschool Children, and Their Families

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Executive Summary

The purpose of this study was to examine the use of community resources and supports outside of formal infant/toddler and preschool programs for children with disabilities. Data on community resource utilization were gathered for sixteen months from parents of 135 infants/toddlers and 148 preschool children. Resources included child care, child therapy services, family need and support programs, health/mental health programs, recreational/socialization programs, and parent employment/education programs. Findings indicated that: (1) the majority of families (i.e., 82% of infants/toddlers and 70% of preschoolers) used community resources at least once over the sixteen month period; (2) the proportion of families using resources increased over time (i.e., 78% to 91% for infants/toddlers; 64% to 75% for preschoolers); (3) child care services were the most frequently utilized resource(i.e., 55% for infants/toddlers and 50% for preschoolers), and the use of informal systems (family member or friend) was more prevalent than the use of formal systems; (4) approximately 34% of infants/toddlers and 39% of preschoolers received additional child therapy services; and (5) the use of child-centered services exceeded the use of family-centered services. Significant variability was also observed among the three study states regarding resource utilization which suggests that the community exerts a significant influence on the availability and utilization of child and family resources. Overall, findings imply that communities and neighborhoods are becoming a significant part of the early childhood experience, and future descriptive and outcome studies will need to account for this broader universe of resources that families with young children with disabilities have rightfully gained access to.

Beyond Early Intervention: Utilization of Community Resources and Supports by Families with Young Children with Disabilities

The public investment in early childhood programs has burgeoned over the last three decades. This enhanced commitment is evident in substantial increases in expenditures in Head Start, pre-kindergarten programs for children presumed to be at high risk for school failure, tax credits to assist families to purchase child care, family support and preservation programs, and programs that serve infants and preschool children with disabilities (Gomby, Larner, Stevenson, Lewit, and Behrman, 1995). Such investments are grounded in an ever increasing body of scientific evidence which suggests that high quality early childhood programs are associated with long term academic and social benefits for children and their families (Burchinal, Roberts, Nabors, and Bryant, 1996; Barnett, 1995; Farran, 1990).

Numerous studies exist that have examined the efficacy of early intervention efforts. In investigations that have studied children from impoverished environments (Campbell and Ramey, 1994; Martin, Ramey, and Ramey, 1990) as well as those with developmental disabilities (Spiker and Hopmann, 1997; Harris, 1997), the methodologic and analytic approach has focused on the association between outcomes and intervention exposure. That is, studies have attempted to account for the degree of exposure to an intervention that children have received, however, little attempt has been made to identify resources and services that families use beyond these programs and their influence on outcomes.

For children with disabilities, the utilization of resources beyond the boundaries of early intervention programs is not trivial. For example, in a comprehensive study of 190 infants with motor impairments and developmental delay (Shonkoff, Hauser-Cram, Krauss and Upshur, 1992), utilization of a wide variety of community resources was common, and in fact, increased

after one year of involvement with early intervention programs. Services frequently used included child therapy, child care, family support, and a variety of other entitlement services (e.g., WIC, AFDC, SSI, food stamps). In a study that evaluated case management services for families with children with developmental delay and chronic medical conditions, Marcenko and Smith (1992) reported that respite care services, nursing services, training in child care, educational, and transportation services were frequently utilized, particularly when families received family-centered support in accessing these services. Families, however, also reported high levels of ongoing, unmet needs for recreational services, life planning, legal services, child care, and speech therapy.

While some evidence exists regarding the factors that contribute to service utilization within the early intervention system (Shonkoff et al., 1992; Kochanek and Buka, 1997a; Kochanek and Buka, 1997b), scant information is available with respect to those services that are accessed by families beyond the early intervention program. As such, the purpose of this study was to examine the use of community resources and supports outside of the early intervention and preschool program. Specific questions that this study addressed were as follows:

> What is the degree of utilization of various community resources and services by children and families beyond early intervention and preschool programs?
>
> Is there evidence of variability in community resource utilization over time and if so, in which resource and support categories?

Method

Study Sites

Data reported in this paper are part of a larger study (Early Childhood Research Institute: Service Utilization) that was designed to identify and understand patterns of service utilization

by families with infants and preschool children with disabilities. With regard to the process used to select communities in this study, Advisory Committees were formed in each study state (i.e., Colorado, North Carolina, Pennsylvania) that were comprised of state officials, families, program administrators, and service providers. The committees nominated diverse communities based on population density, sociodemographic characteristics, and resource availability. All nominated communities were to be exemplary in terms of the values and concepts (e.g., community inclusion, service integration, family-centeredness) underlying Part H of IDEA.

In each state, the Advisory Committee nominated 12-15 communities. Study investigators, after reviewing key sociodemographic, fiscal, geographic, and contextual factors, selected three diverse communities in each state. An attempt was made to select one community in each state with high population density and resource availability, one with moderate population density and resource availability, and one with low population density and resource availability.

Table 1 provides a descriptive portrait of each of the nine study communities, and reveals significant variability in resident population, the percent of this population represented by racial minorities, and the prevalence of low birthweight and single parent families. Also of noteworthy importance is that the prevalence of childhood poverty ranged from 10%-21% across study sites.

Table 1
Descriptive Portrait of Study Communities

	COLORADO			NORTH CAROLINA			PENNSYLVANIA		
	HI	MOD	LOW	HI	MOD	LOW	HI	MOD	LOW
Total Population	225,339	32,273	6,007	347,420	59,013	61,704	1,336,446	89,994	78,097
Total Minority (%)	10.5	13.9	25.1	28.6	19.9	5.7	13.1	2.5	0.6
% Child Poverty	9.5	19.8	16.4	14.3	17.7	12.9	17.1	21.0	18.6
Per Capita Income	$17,359.	$9,971.	$11,269.	$18,117.	$16,274.	$13,370.	$15,115.	$10,260.	$10,430.
Children in Single Parent Families (%)	16.4	28.5	23.8	23.0	20.0	15.0	23.9	16.7	16.4
Low Birthweight Rate (%)	6.4	9.3	15.8	8.6	7.7	6.0	8.0	6.0	6.1

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Sample

One hundred thirty-five infants/toddlers who were enrolled in early intervention programs in these nine study communities constituted the sample for this investigation. Whereas the mean age of children studied was 21.8 months at the time of data collection, the mean age of referral to programs was 9.6 months. Fifty-six percent of the children were male, and 66% were White. Thirty-seven percent of the sample demonstrated low need/complexity, 40% moderate, and 23% high need/complexity. Need/complexity categorizations were based on four factors: child developmental status, child health status, overall family needs, and number of agencies and programs with which the family was affiliated. Primary service providers determined child need/complexity classifications. For approximately 30% of the sample, Institute staff who were blind to these ratings conducted in-home interviews with families and based on these interviews, provided need/complexity ratings. Inter-rater agreement was good with 66% of the ratings identical and 94% within one rating category (kappa = .46, $p < .001$).

With regard to the mothers of these children, mothers were, on average, 29.8 years old (SD = 7.5 years). Fifty-one percent of the mothers has attained a high school degree or less, and 24% were college graduates. The majority (i.e., 59%) of mothers did not work outside of their homes. Finally, 59% of the families reported annual incomes near or below the poverty line (< $20,000./year).

For the preschool cohort, 148 children were studied. The mean age was 46.8 months, whereas the mean age of referral to the programs was 35.6 months. Sixty-four percent of the children were male, and 73% were White. With regard to need/complexity, 27% were low, 37% moderate, and 36% high. For mothers of these preschoolers, 55% had attended high school or

attained a high school diploma, 59% were not employed outside of their homes, and 50% reported annual incomes of less than $20,000./year.

Measure of Utilization of Community Resources and Supports

Information regarding family use of resources and supports beyond the early intervention and preschool systems was collected for one week per month for a sixteen month period (i.e., May, 1994 to August, 1995). Data were gathered in one of three ways: (1) mothers completed the resources and supports protocol independently each month; (2) primary service providers in collaboration with mothers completed the protocol on a monthly basis; (3) in-state resident research assistants contacted parents by phone to ascertain which specific resources had been used. Despite the method of data reporting, the principal question to parents remained the same: "Which of the following resources did you use at least once during this specific week?" Since it was not possible to assess the validity of information reported through either a record review or site visitation, the degree to which these data fully reflect all resources used by children and families is indeterminable.

Infants and Toddlers

For infants and toddlers, the Child and Family Resources and Supports protocol (Appendix A) included 41 different services or supports that families with infants and toddlers might utilize in their daily lives. The services ranged from formal services (e.g., physical and speech/language therapy, child care, WIC, additional schooling or vocational training for parents, respite care) to informal resources (e.g., neighborhood play groups). The 41 individual items were categorized into eight conceptually discreet categories for analysis. These categories included child care (items 1-5), child therapy (items 6-10), child recreation/socialization activities (items 11-13), family needs (items 15-21), parent employment and education (items 22-

25), family support (items 26-29), health/mental health (items 30-35), and informal community resources (items 36-40). Items 14 and 41 were combined to form a category described as "other." The categories and the individual resources and supports included within each were as follows.

Child Care
- Family based child care (licensed)
- Center based child care (licensed)
- Child care by a family member, friend, or neighbor
- Parent Child Center
- Family Center

Child Therapy
- Speech/language therapy
- Physical therapy
- Occupational therapy
- Psychologic services
- Home health care services (child)

Child Recreation/Socialization Activities
- Neighborhood play group
- Recreational programs (e.g., swimming or gymnastics classes)
- Other social/learning activities (e.g., library story hours, church groups)

Family Needs
- Housing
- Transportation
- Clothing
- Phone service
- Emergency fuel program
- Food/adequate nutrition
- WIC (Women, Infants, and Children program)

Parent Employment/Education
- Employment search programs for parents
- Parent education programs
- Additional education for parents (GED, college degree)
- Vocational training/rehabilitation for parents

Family Support
- Financial counseling
- Legal assistance services
- Respite care
- Homemaking services

Health/Mental Health

Information on health insurance benefits and programs
Primary health care services
Medical specialty services
Home health care services (family)
Mental health services
Substance abuse treatment

Informal Community Resources

Self-help groups (e.g., substance abuse, weight reduction)
Enhanced informal social support system
Information on community-based resources
Opportunities for socialization with other adults and families
Recreational opportunities

Other

In reporting utilization of the above resources, parents indicated whether or not they utilized any one of the 41 services listed during the given data collection week. These resources were not included within IFSPs, and early intervention programs did not assume responsibility for payment of these resources. The form allowed for indication of the use of various services, but did not require specification of the actual frequency with which any resource was used.

Preschool

With regard to the preschool sample, 16 different resources or supports were included (Appendix B). Again, families reported the specific resource items used at least once during the specific week of data collection. The 16 service items were reduced to four conceptually discreet categories. These included child care/preschool (items 1-6), child therapy (items 7-10), child recreation/socialization activities (items 12-14), and other (items 11, 15, 16). The categories and specific resources and supports contained within each were as follows.

Child Care/Preschool

Family based child care (licensed)
Center based child care (licensed)
Child care by a family member, friend, or neighbor
Nursery school
Family Center
Head Start

Child Therapy

Speech/language therapy
Physical therapy
Occupational therapy
Psychologic services

Child Recreation/Socialization Activities

Neighborhood play group
Recreational programs (e.g., swimming or gymnastics classes)
Other social/learning activities (e.g., library story hours; church groups)

Other

Home health care services
Other services
Transportation

Data Analysis

For data analytic purposes, the number of "times" resources were used refers to the number of forms over sixteen months in which each family indicated that they had used a specific resource. Again, the nature and design of the form precluded any more precise definition of the volume of resources and supports utilized. Data are presented for two cohorts for both infants/toddlers and preschoolers: (1) all families enrolled in programs each month over sixteen months; and (2) the same families enrolled in programs for the entire sixteen month period.

Results

Infant/Toddler Sample

Data that present the percentage of families using various resource categories each quarter are portrayed in Figure 1 (all families) and Figure 2 (same families) respectively. It is important to note that findings for each quarter were derived from four weeks of data (i.e., one week out of each month), and represent the average percentage of families who reported using

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specific resources over this time period. For all families enrolled each month over this sixteen month period (Figure 1), findings indicated that the most frequently used service was child care (mean = 55% over four quarters), followed by family needs resources (39%), child therapy (34%), and child recreation/socialization (24%). Least frequently used resources included family support resources (9%) and parent education/employment programs (14%).

Data that present comparable findings for eighty-one infants/toddlers enrolled in programs for the entire sixteen month period are presented in Figure 2. Of interest is that similar findings to that reported above are observed, with the most frequently used resources involving child care (52%), family needs resources (38%), and child recreation/socialization (22%). Of significance is that approximately one-third of families elected to purchase additional child therapy services (i.e., motor and speech/language therapy) beyond that provided by the early intervention program. It is also significant to note that the proportion of families using community resources increased over time, particularly in the areas of child care, child therapy, child recreation/socialization, and health care.

Figure 1
Percentage of All Infant/Toddler Study Families Using Community Resources Over (Four) Four-Month Time Periods

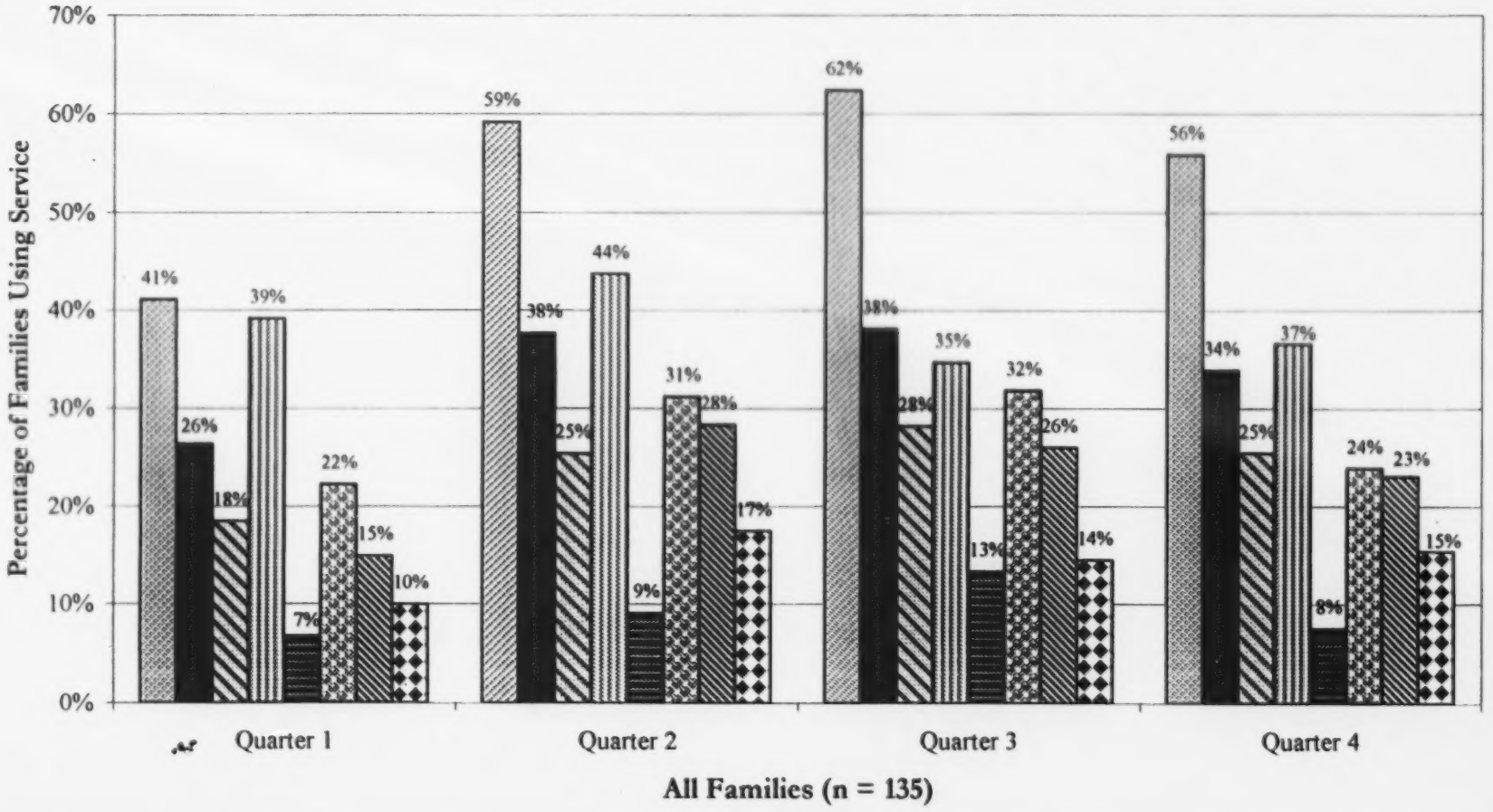
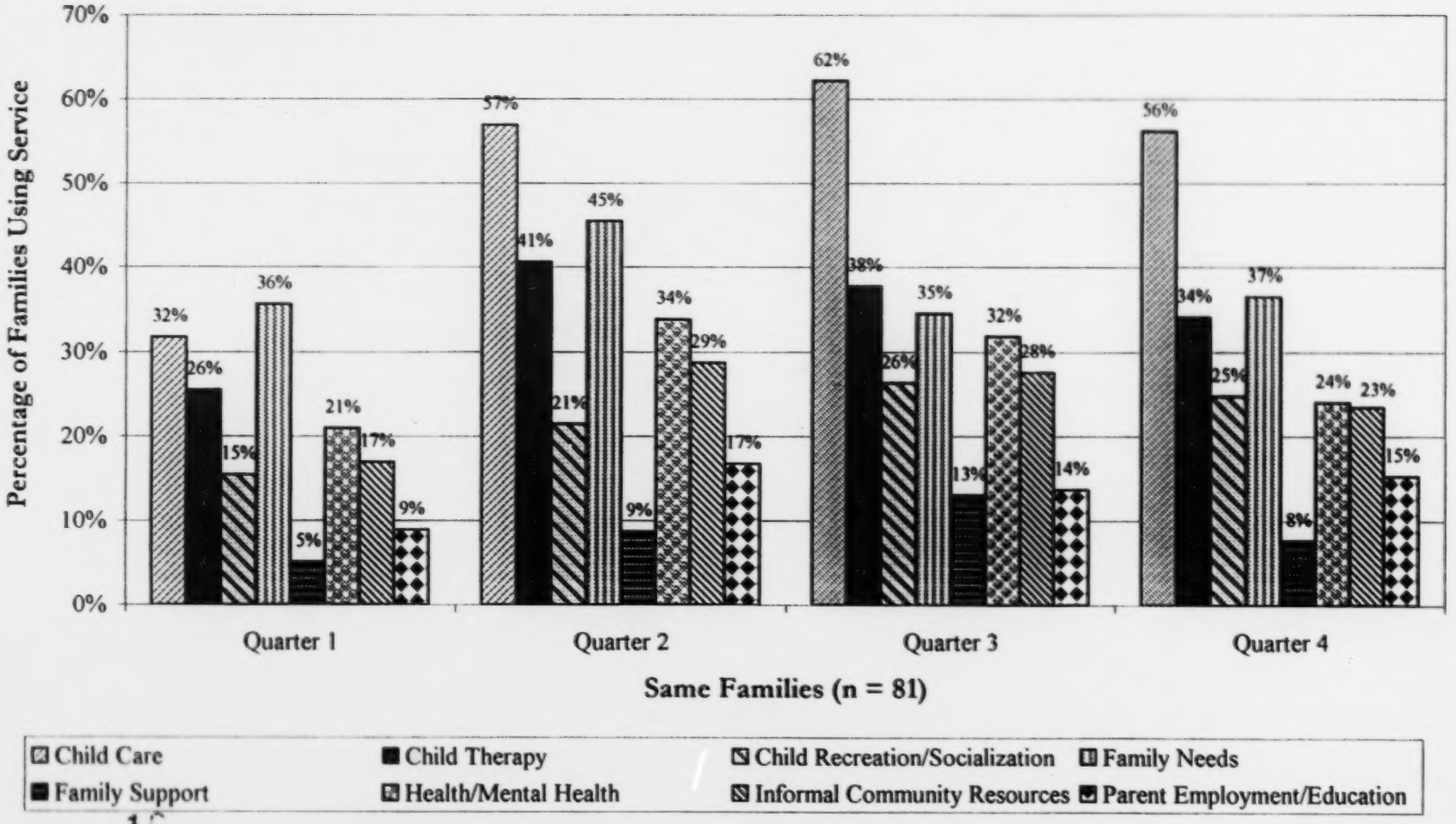


Figure 2
Percentage of the Same Infant/Toddler Study Families Using Community Resources Over (Four) Four-Month Time Periods



Data that present the percentage of families using specific service types for the first week of each four-month time period are presented in Tables 2 and 3 respectively. For resource categories most frequently used as reported above (i.e., child care, family needs, child therapy, child recreation/socialization), findings indicated that one or two resources accounted for greatest utilization. More specifically, within the area of child care, "child care by family member or friend" was the most common mode of care accessed, and in fact, was nearly twice as prevalent as care provided within licensed, center-based settings, and substantially more prevalent than licensed, family-based child care. In short, informal child care arrangements were much more common for families in this study than were formal family and center-based systems of care.

Within the area of family needs resources, utilization of the Women, Infants, and Children Program (WIC) was most frequently reported. For child therapy, the use of motor and speech/language therapists was approximately equal. Finally, for child recreation/socialization activities, informal, neighborhood play groups and other social/learning activities (e.g., library story hours) were most prevalent. It is also important to note that substantially similar findings are evident for both all families and the same families enrolled in programs over time.

Table 2
Percentage of All Infant/Toddler Study Families Using Specific Resources Within First Week of (Four) Four-Month Time Periods

All Families

	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
CHILD CARE				
Center based	32%	35%	23%	15%
Family member	54%	75%	72%	83%
Family based	16%	6%	5%	4%
Family Center	5%	17%	7%	7%
Parent/Child Center	2%	6%	18%	7%
CHILD THERAPY				
Home health care services (child)	21%	17%	28%	10%
Occupational therapist	44%	40%	47%	47%
Physical therapist	56%	50%	61%	67%
Psychologic services	0%	0%	6%	10%
Speech/Language therapist	32%	47%	69%	57%
CHILD RECREATION/SOCIALIZATION				
Neighborhood play group	41%	29%	45%	57%
Other Services	11%	21%	3%	5%
Other social/learning activities	48%	50%	61%	81%
Recreational programs	11%	14%	23%	10%
FAMILY NEEDS				
Clothing	6%	12%	16%	30%
Emergency fuel program	2%	2%	21%	7%
Food/adequate nutrition	17%	26%	26%	33%
Housing	17%	17%	18%	23%
Phone Service	2%	7%	13%	30%
Transportation	25%	21%	32%	33%
WIC	77%	83%	82%	57%

	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
FAMILY SUPPORT				
Financial counseling	13%	33%	20%	0%
Homemaking services	0%	17%	7%	25%
Legal assistance services	67%	0%	27%	25%
Respite care	100%	83%	73%	50%
HEALTH/MENTAL HEALTH				
Home health care services (family)	6%	4%	6%	4%
Information on health insurance	43%	33%	50%	52%
Medical specialty services	34%	37%	44%	32%
Mental health services	11%	19%	11%	4%
Primary health care services	26%	48%	44%	44%
Substance abuse treatment	3%	4%	0%	0%
INFORMAL COMMUNITY RESOURCES				
Informal social support system	19%	14%	31%	28%
Information on community-based resources	38%	45%	39%	28%
Opportunities for socialization	48%	55%	58%	83%
Recreational opportunities	33%	27%	42%	44%
Self-help groups	14%	18%	11%	11%
PARENT EMPLOYMENT/EDUCATION				
Additional education for parents	25%	35%	33%	25%
Employment search programs for parents	42%	24%	20%	58%
Parent education programs	50%	59%	53%	42%
Vocational training/rehabilitation for parents	8%	0%	7%	0%

Table 3
Percentage of the Same Infant/Toddler Study Families Using Specific Resources Within First Week of (Four) Four-Month Time Periods

Same Families

	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
CHILD CARE				
Center based	23%	27%	21%	16%
Family member	65%	76%	72%	82%
Family based child care (licensed)	8%	6%	6%	4%
Family Center	8%	18%	9%	7%
Parent/Child Center	4%	6%	21%	7%
CHILD THERAPY				
Home health care services (child)	18%	23%	25%	10%
Occupational therapist	53%	50%	57%	48%
Physical therapist	65%	59%	71%	66%
Psychologic services	0%	0%	4%	10%
Speech/Language therapist	18%	36%	71%	59%
CHILD RECREATION/SOCIALIZATION				
Neighborhood play group	43%	67%	57%	60%
Other Services	0%	0%	0%	0%
Other social/learning activities	50%	50%	52%	80%
Recreational programs	21%	17%	26%	10%
FAMILY NEEDS				
Clothing	3%	16%	13%	28%
Emergency fuel program	0%	0%	27%	3%
Food/adequate nutrition	10%	32%	33%	34%
Housing	21%	19%	20%	21%
Phone Service	0%	6%	13%	31%
Transportation	24%	29%	33%	31%
WIC	79%	81%	77%	59%

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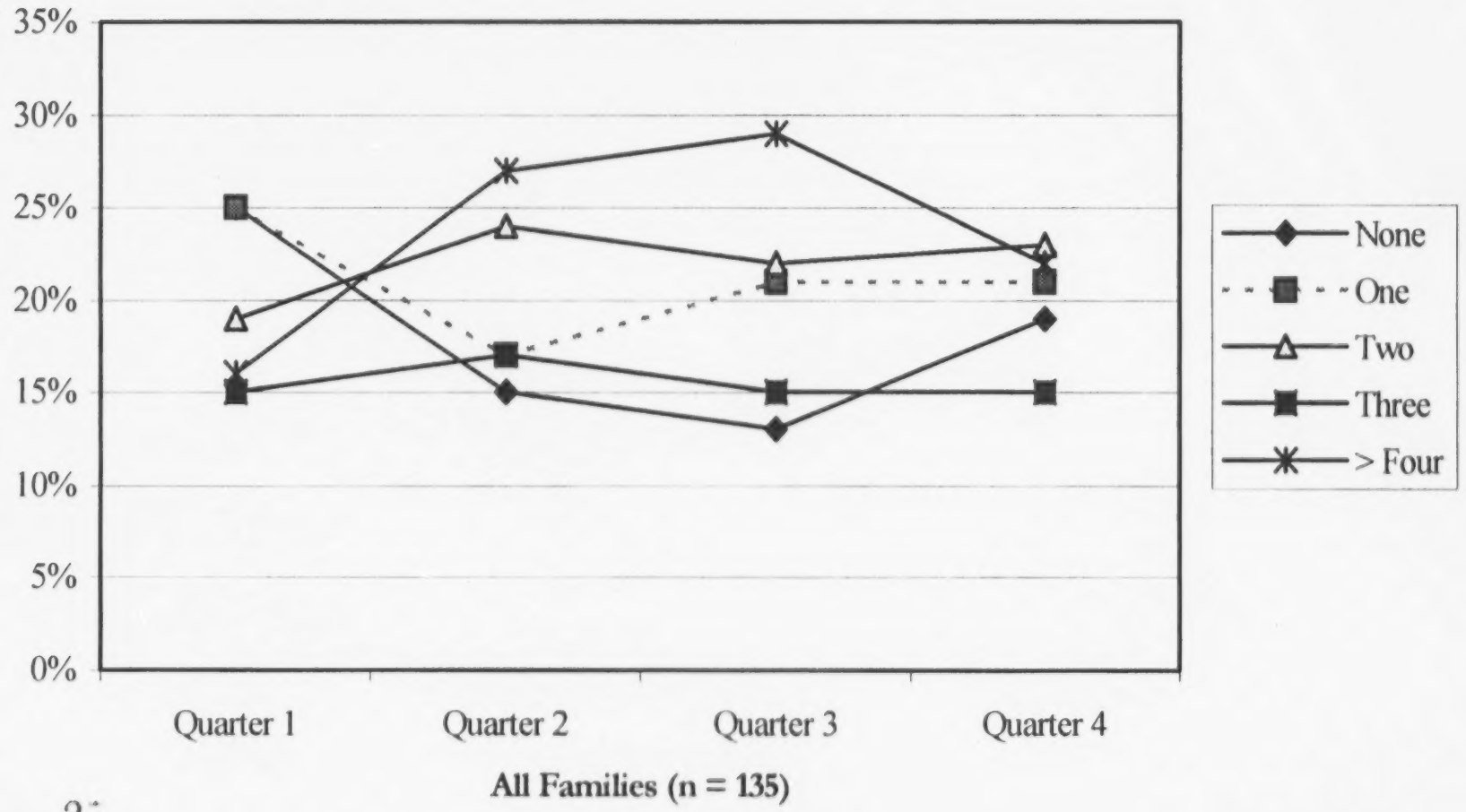
	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
FAMILY SUPPORT				
Financial counseling	0%	40%	25%	0%
Homemaking services	0%	20%	8%	25%
Legal assistance services	40%	0%	25%	25%
Respite care	60%	80%	67%	50%
HEALTH/MENTAL HEALTH				
Home health care services (family)	11%	4%	0%	4%
Information on health insurance	26%	35%	50%	54%
Medical specialty services	47%	43%	47%	33%
Mental health services	11%	17%	10%	4%
Primary health care services	32%	48%	50%	42%
Substance abuse treatment	5%	4%	0%	0%
INFORMAL COMMUNITY RESOURCES				
Enhanced informal social support system	23%	13%	35%	28%
Information on community-based resources	54%	44%	42%	28%
Opportunities for socialization	54%	50%	58%	83%
Recreational opportunities	31%	31%	45%	44%
Self-help groups	15%	19%	10%	11%
PARENT EMPLOYMENT/EDUCATION				
Additional education for parents	29%	42%	42%	18%
Employment search programs for parents	29%	17%	17%	55%
Parent education programs	43%	58%	50%	45%
Vocational training/rehabilitation for parents	14%	0%	8%	0%

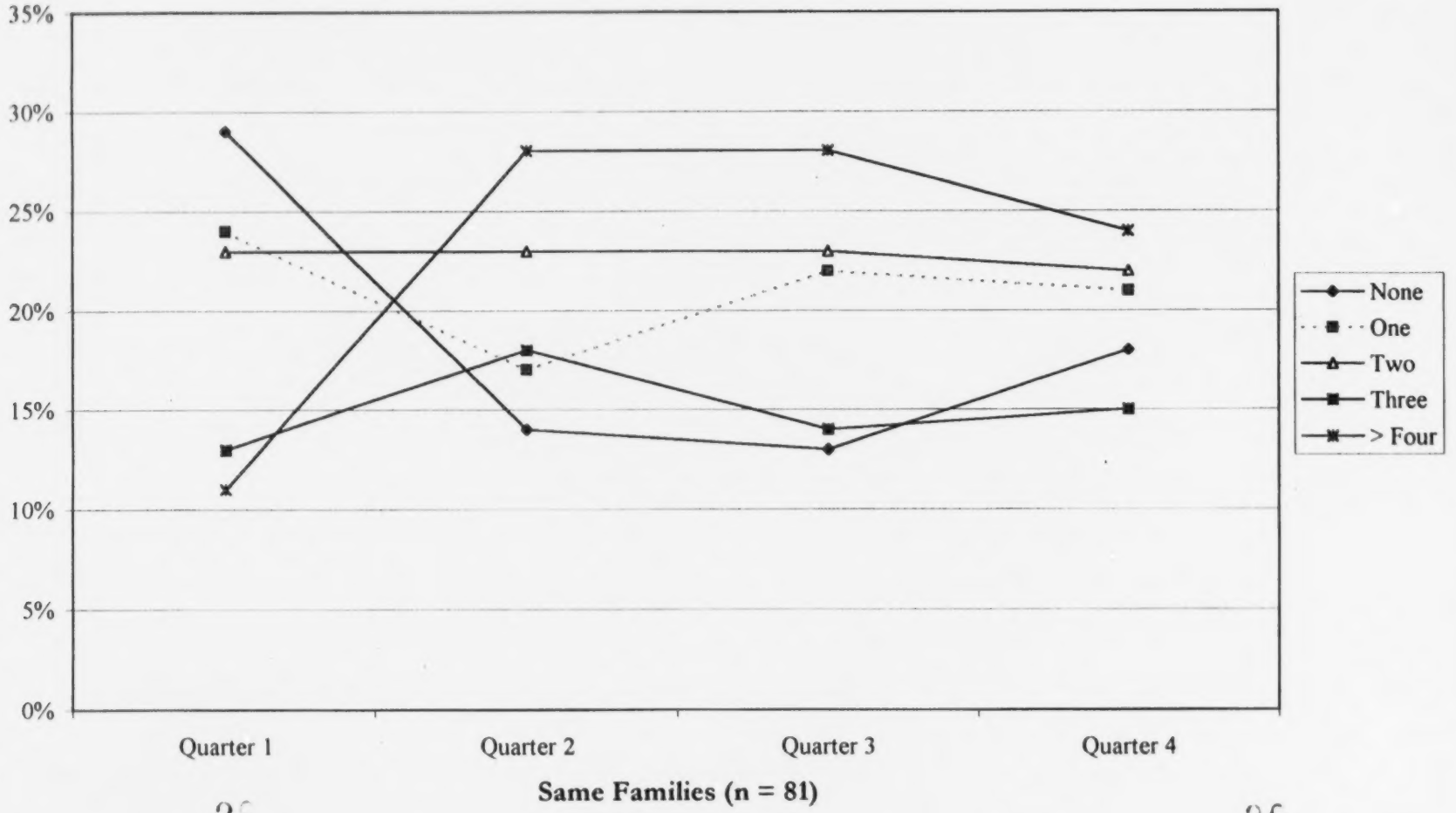
With regard to the utilization of multiple service categories concurrently over time, data in Figures 3 and 4 present findings for both all and same families respectively. Of interest is that the percentage of families using four or more service categories concurrently nearly doubles over time. That is, significant increases are observed in the number of families who access a myriad of services external to the early intervention program. Conversely, the proportion of families using no or only one service category decreases over time.

Figure 3
Percentage of <u>All</u> Infant/Toddler Families Using
Multiple Service Categories Over (Four) Four-Month Time Periods



All Families (n = 135)

Figure 4
Percentage of the Same Infant/Toddler Study Families Using Multiple Service Categories Over (Four) Four-Month Time Periods



Same Families (n = 81)

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Finally, it is important to note that the utilization of resources beyond early intervention programs was not consistent among states. For example, data in Table 4 reveal that over a sixteen month period for all families enrolled in programs, more families in North Carolina utilized child care (60%) and family needs resources (49%) than in either Colorado or Pennsylvania. Alternatively, a greater percentage of families in Colorado used child therapy services (50%) and child recreation/socialization activities (33%) than in the other two states. Finally, a greater proportion of families in Pennsylvania used parent education/employment programs (26%) than in either Colorado or North Carolina.

Table 4
Percentage of Infant/Toddler Families Using Community Resources by State Over Sixteen Months

	MO 1	MO 2	MO 3	MO 4	MO 5	MO 6	MO 7	MO 8	MO 9	MO 10	MO 11	MO 12	MO 13	MO 14	MO 15	MO 16
							Colorado									
Child Care	29%	32%	31%	47%	41%	80%	58%	48%	70%	62%	59%	45%	55%	63%	55%	50%
Child Therapy	45%	41%	44%	47%	50%	80%	69%	44%	78%	76%	64%	60%	55%	42%	45%	50%
Child Recreation/Socialization	11%	24%	17%	11%	9%	52%	38%	41%	65%	62%	45%	35%	30%	32%	30%	33%
Family Needs	18%	19%	22%	39%	32%	36%	27%	22%	35%	31%	27%	15%	25%	21%	25%	28%
Family Support	18%	5%	8%	8%	9%	16%	15%	19%	43%	34%	18%	25%	10%	11%	10%	11%
Health/Mental Health	26%	16%	14%	19%	18%	48%	46%	37%	65%	48%	23%	15%	30%	21%	35%	28%
Informal Community Resources	13%	14%	8%	6%	14%	16%	50%	41%	65%	59%	18%	20%	30%	26%	25%	17%
Parent Employment/Education	5%	3%	3%	3%	9%	24%	27%	4%	13%	10%	9%	0%	0%	5%	5%	0%
							North Carolina									
Child Care	67%	49%	48%	55%	60%	71%	64%	62%	60%	62%	69%	73%	60%	68%	55%	36%
Child Therapy	14%	18%	22%	45%	35%	27%	31%	33%	28%	26%	36%	36%	33%	32%	34%	24%
Child Recreation/Socialization	29%	27%	26%	18%	12%	22%	21%	26%	25%	8%	17%	18%	20%	26%	24%	20%
Family Needs	57%	59%	62%	82%	58%	54%	60%	43%	40%	28%	36%	39%	43%	42%	45%	40%
Family Support	14%	8%	2%	0%	5%	5%	12%	7%	8%	5%	8%	9%	3%	6%	10%	12%
Health/Mental Health	33%	35%	28%	36%	35%	24%	26%	33%	38%	38%	36%	27%	40%	26%	21%	16%
Informal Community Resources	22%	14%	20%	27%	30%	20%	19%	21%	30%	18%	17%	12%	20%	16%	17%	16%
Parent Employment/Education	4%	8%	8%	18%	19%	12%	12%	12%	8%	3%	6%	12%	17%	6%	10%	12%
							Pennsylvania									
Child Care	29%	25%	35%	44%	59%	52%	41%	47%	65%	74%	70%	32%	68%	50%	63%	48%
Child Therapy	22%	17%	18%	8%	18%	14%	29%	20%	23%	26%	15%	20%	36%	25%	19%	26%
Child Recreation/Socialization	13%	6%	10%	10%	18%	10%	18%	20%	19%	24%	11%	24%	36%	14%	22%	17%
Family Needs	40%	31%	27%	28%	45%	33%	35%	53%	45%	41%	41%	28%	48%	39%	33%	35%
Family Support	2%	4%	6%	3%	9%	10%	0%	0%	6%	3%	11%	8%	4%	4%	7%	4%
Health/Mental Health	20%	17%	18%	13%	36%	19%	24%	20%	19%	18%	37%	20%	28%	18%	15%	13%
Informal Community Resources	11%	10%	20%	18%	27%	33%	24%	73%	29%	24%	19%	20%	24%	25%	30%	35%
Parent Employment/Education	18%	13%	16%	21%	32%	43%	24%	7%	29%	29%	30%	28%	28%	21%	30%	39%

Preschool Sample

Data that present the proportion of families with preschool children using various resource categories each quarter are portrayed in Figure 5 (all families enrolled each month) and Figure 6 (same families enrolled over four quarters). Again, findings for each quarter were derived from four weeks of data (i.e., one week out of each month), and represent the average percentage of families who reported using specific resources over this time period. For all families enrolled each quarter (Figure 5), data indicated that child care (49%) was used by the greatest percentage of families, followed by child therapy (39%) and child recreation/socialization activities (26%).

While comparable findings are evident for the same families enrolled in programs for the entire sixteen month period (Figure 6), changes in service utilization over time for this group are significant. For example, utilization of child care services nearly doubles from Quarter 1 to Quarter 4 (32% to 59%), and similarly, use of child recreation/socialization programs increases threefold (15% to 48%). Increases are also evident in the percentage of families who elected to purchase child therapy services (motor and speech/language therapy) above and beyond that provided by the school district.

Figure 5
Percentage of All Preschool Study Families Using Community Resources Over (Four) Four-Month Time Periods

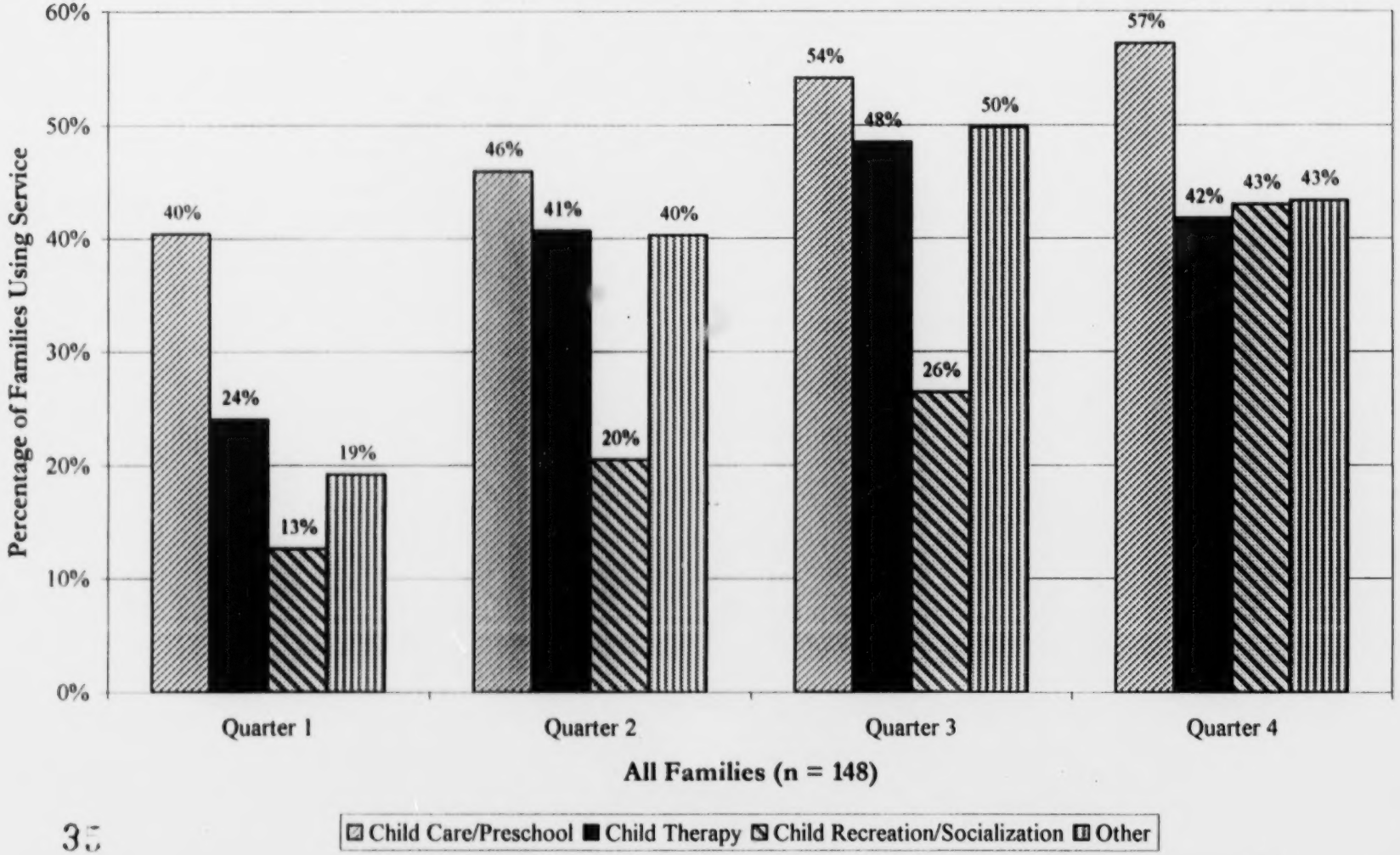
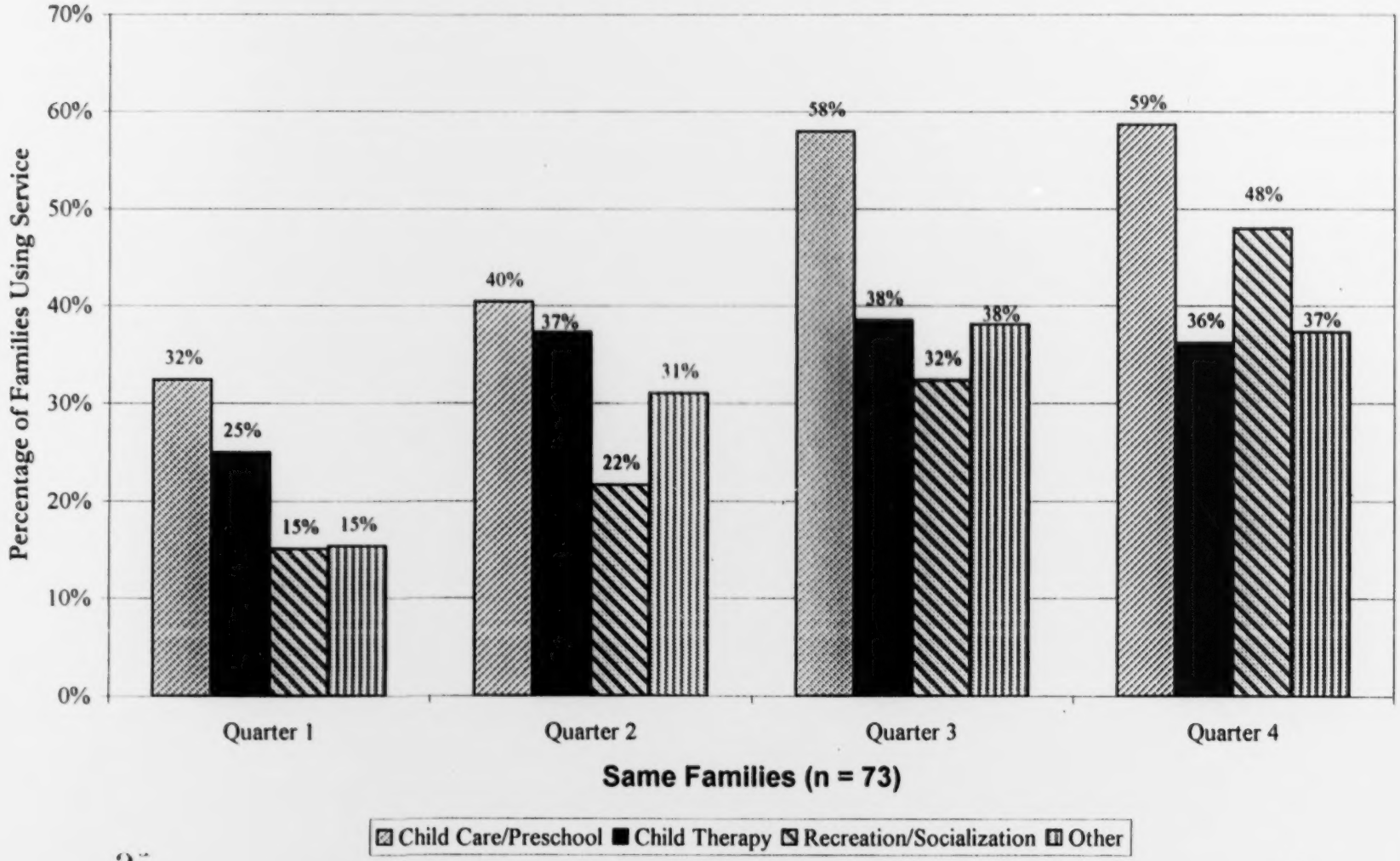


Figure 6
Percentage of the Same Preschool Study Families Using Community Resources Over (Four) Four-Month Time Periods



Data that present the proportion of families using specific service types are presented in Tables 5 (all families) and 6 (same families). Within the area of child care, of interest is that the percentage of families using informal sources of care (family members or friends) exceeds that of families using formal programs (e.g., licensed, center-based, and nursery school programs and Head Start). Also of noteworthy importance within the area of child care is that the most significant increases in utilization over time for the same families (Table 6) are observed in informal systems (i.e., 27% to 74%) rather than formal systems.

Within the area of child therapy, use of motor therapists is approximately equal to that of speech/language therapists (Table 5). Increases in the use of both motor and language therapists are observed when the same families are examined over the sixteen month period.

Finally, within the area of child recreation/socialization, the use of informal, neighborhood play groups appears to be the primary resource utilized over time.

Table 5
Percentage of All Preschool Study Families Using Specific Resources Within First Week of (Four) Four-Month Time Periods

All Families

	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
CHILD CARE				
Center based	40%	33%	29%	26%
Family member	37%	47%	64%	66%
Family based	3%	6%	1%	3%
Family Center	5%	11%	10%	9%
Head Start	25%	33%	32%	21%
Nursery School	8%	18%	14%	18%
CHILD THERAPY				
Occupational Therapist	33%	38%	37%	44%
Physical Therapist	37%	33%	28%	39%
Psychologist	15%	2%	1%	12%
Speech/Language Therapist	74%	94%	89%	82%
CHILD RECREATION/SOCIALIZATION				
Neighborhood play group	65%	55%	61%	72%
Other social/learning activities	8%	14%	21%	5%
Recreational programs	31%	32%	27%	28%
OTHER				
Home health care services	46%	41%	42%	33%
Other social/learning activities	21%	25%	19%	29%
Transportation	52%	69%	65%	75%

Table 6
Percentage of the Same Preschool Study Families Using Specific Resources Within First Week of (Four) Four-Month Time Periods

Same Families

	Week 1 Quarter1	Week 2 Quarter 2	Week 3 Quarter 3	Week 4 Quarter 4
CHILD CARE				
Center based	20%	22%	21%	20%
Family member	27%	59%	72%	74%
Family based	7%	15%	3%	6%
Family Center	7%	22%	18%	17%
Head Start	20%	33%	26%	11%
Nursery School	33%	37%	28%	34%
CHILD THERAPY				
Occupational Therapist	44%	52%	41%	57%
Physical Therapist	44%	43%	37%	43%
Psychologist	22%	4%	4%	13%
Speech/Language Therapist	67%	100%	85%	87%
CHILD RECREATION/SOCIALIZATION				
Neighborhood play group	67%	64%	56%	75%
Other social/learning activities	0%	7%	22%	0%
Recreational programs	33%	29%	28%	33%
OTHER				
Home health care services	42%	50%	63%	42%
Other social/learning activities	33%	44%	25%	37%
Transportation	33%	61%	47%	68%

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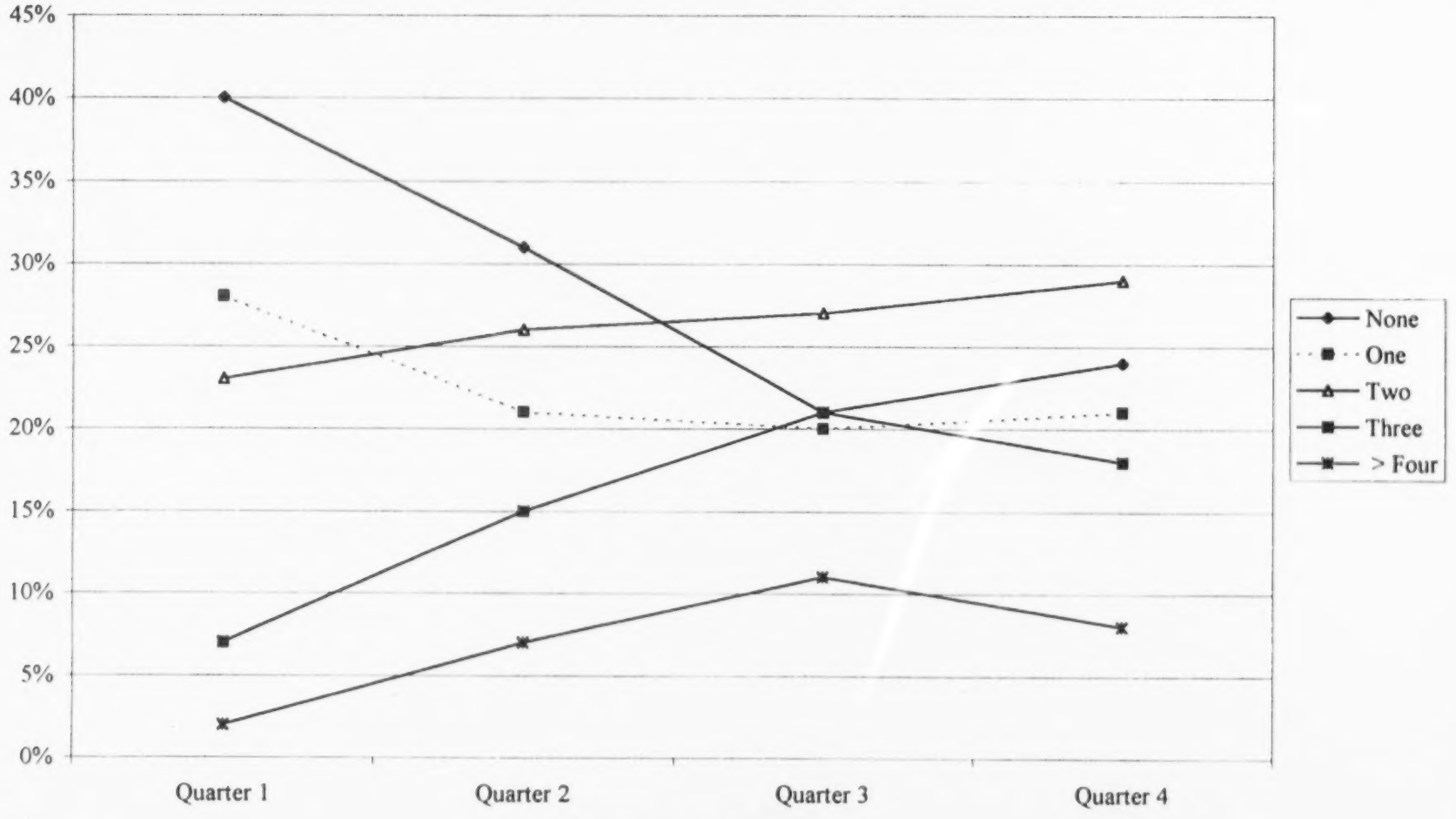
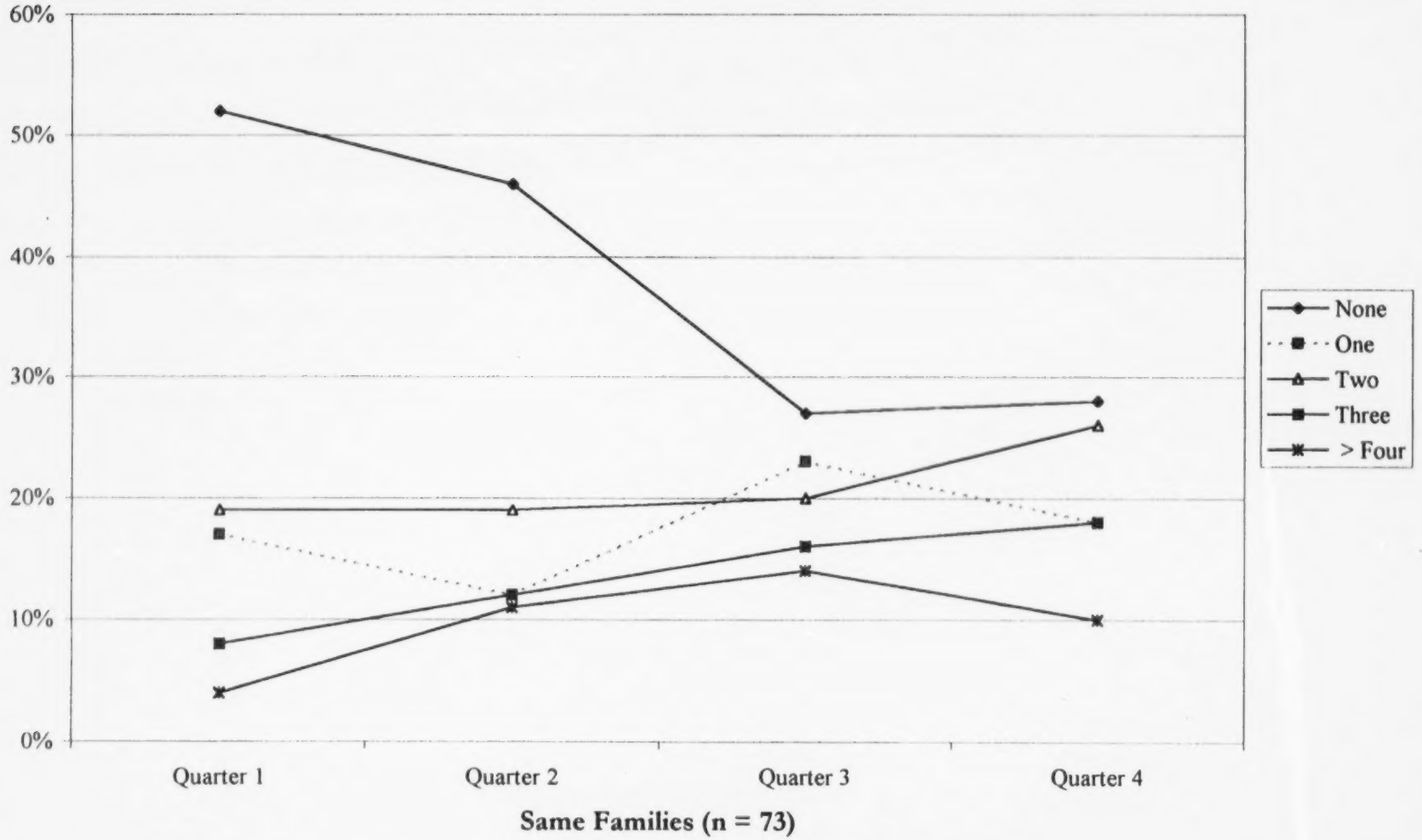
With regard to the utilization of multiple service categories concurrently over time, data in Figures 7 and 8 present findings for all and same families respectively. For all families enrolled in programs each month over (four) quarterly time periods, findings indicated that approximately 70% of families used at least one service within each time period examined (range = 60% - 78%). When the same families are examined longitudinally (Figure 8), data revealed an increase in the percentage of families using three or more service categories concurrently, and a substantial decrease in the percentage of families using no community based resources.

Table 7
Percentage of All Preschool Study Families Using Multiple Service Catetgories Over (Four) Four-Month Time Periods



All Families (n = 148)

Table 8
Percentage of the Same Preschool Study Families Using Multiple Service Categories Over (Four) Four-Month Time Periods



Same Families (n = 73)

Finally, inter-state differences previously noted in the utilization of community based resources by infants/toddlers and their families were also evident for the preschool sample. More specifically, utilization of child care/preschool services was greater in Colorado (57%) than in North Carolina (44%) or Pennsylvania (45%). Similarly, utilization of child therapy services was also more prevalent in Colorado (55%) than in North Carolina (33%) or Pennsylvania (31%). Finally, utilization of child recreation/socialization programs was nearly equal in Colorado (32%) and Pennsylvania (30%) and notably higher than in North Carolina (12%).

Table 9
Percentage of Preschool Families Using Community Resources by State Over Sixteen Months

	MO 1	MO 2	MO 3	MO 4	MO 5	MO 6	MO 7	MO 8	MO 9	MO 10	MO 11	MO 12	MO 13	MO 14	MO 15	MO 16
Colorado																
Child Care/Preschool	24%	48%	47%	33%	46%	67%	45%	32%	48%	68%	74%	79%	79%	76%	80%	70%
Child Therapy	36%	52%	47%	33%	43%	58%	48%	39%	48%	48%	78%	79%	75%	59%	70%	70%
Child Recreation/Socialization	15%	32%	47%	7%	14%	21%	35%	6%	18%	23%	37%	38%	38%	35%	90%	60%
Other	27%	32%	27%	13%	17%	58%	35%	19%	39%	55%	48%	45%	46%	41%	40%	40%
North Carolina																
Child Care/Preschool	63%	64%	21%	49%	46%	41%	45%	45%	50%	42%	46%	35%	34%	37%	---	---
Child Therapy	15%	15%	24%	27%	21%	23%	27%	47%	52%	46%	51%	40%	36%	37%	---	---
Child Recreation/Socialization	16%	7%	3%	0%	7%	13%	18%	27%	14%	12%	11%	14%	13%	15%	---	---
Other	24%	20%	0%	14%	49%	52%	63%	44%	57%	49%	47%	56%	52%	48%	---	---
Pennsylvania																
Child Care/Preschool	35%	48%	15%	8%	53%	42%	35%	57%	63%	63%	57%	54%	57%	27%	69%	33%
Child Therapy	12%	20%	15%	15%	56%	49%	47%	43%	49%	53%	36%	33%	36%	0%	0%	33%
Child Recreation/Socialization	22%	23%	0%	8%	29%	25%	25%	25%	37%	42%	39%	46%	43%	36%	46%	33%
Other	47%	34%	0%	0%	38%	32%	28%	37%	63%	53%	41%	40%	43%	18%	54%	33%

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Discussion

The purpose of this study was to identify the extent to which families with young children with disabilities access community based resources and supports beyond the formal early intervention and preschool systems. Findings indicated that, in fact, families elected to utilize a variety of different services and resources. Major findings were as follows.

Infants/Toddlers

- Approximately 82% of families accessed child and/or family resources and supports at least once outside of early intervention during a sixteen month period.
- Child care, family needs, child therapy, and child recreation/socialization services were the most frequently reported resource categories. Least frequent were family support resources and parent education and employment programs.
- "WIC," informal child care, motor and speech/language therapy, and respite care were the most frequently reported individual resources used.
- The percentage of families using community resources increased over time, particularly in the areas of child care, child therapy, child recreation/socialization, and health care.
- Child care by family member or friend was the most frequently utilized form of child care by families of infants/toddlers.
- Few families utilized services which were parent-focused.
- One third of families purchased additional child therapy for their infants/toddlers, of which physical therapy was the most frequently reported form of therapy used.
- Utilization of services outside of early intervention was not consistent among the three states.

Preschool Children

- Approximately 70% of families accessed child and/or family resources and supports at least once outside of preschool programs during a four month period.

- Child care and child therapy were the most frequently reported resource categories used.
- Utilization of child care and child recreation/socialization activities substantially increased over time for the same families enrolled in programs.
- The percentage of families using informal sources of care exceeded that of families using formal programs.
- Utilization of informal child care, speech/language therapy, and neighborhood play groups were the services used by the greatest percentage of families.
- Utilization of resources beyond formal preschool programs among study states was not consistent.

Several observations are noteworthy with regard to the above findings. First, data clearly indicate that families have gained access to community resources that are intended for all children. This finding suggests that recent policy and programmatic commitments to inclusion appear to be translating into greater opportunities for children with disabilities and their families. Furthermore, early intervention and preschool programs presumably have played a key role in successfully prompting and supporting families to access and utilize community resources.

Second, the frequent use of community based child care programs is particularly encouraging. Given the growing body of literature that describes the benefits of integration, particularly within the areas of social skills and language competency (Strain, 1990; Odom, McConnel, and Chandler, 1993; Bricker, 1995; Peck, Odom, and Bricker, 1993; Strain, 1995; Cole, Mills, Dale, and Jenkins, 1991), this is a noteworthy finding.

Within the area of child care, it is interesting to note that informal systems (family member or friend) were used more frequently than formal systems. While there are data which indicate that this is an expected finding (i.e., informal child care arrangements were twice as prevalent as formal services in a study by Hofferth, Brayfield, Deich, and Holcomb, 1991), other plausible factors must also be considered. For example, with respect to the issue of availability,

child care for infants and toddlers is particularly difficult to locate due to space and staffing requirements in licensed programs. Parents of children with disabilities are further hampered by the fact that many child care centers do not accept children with disabilities (Kisker, Hofferth, Phillips, and Farquhar, 1991).

Affordability is a second major concern for families. For all families, infant/toddler care is expensive due to lower child/staff ratios. Affordability is also linked to a family's financial circumstances; as family income decreases, the proportion of income spent on child care increases (Willer, Hofferth, Kisker, Divine-Hawkins, Farquhar, and Glantz, 1991). Since many of the families (59%) in this study were at or near poverty level, it is not surprising that they were often unable to participate in the formal child care system and needed to rely on informal family care arrangements.

A final factor for consideration in decision making by families is quality. Quality of child care varies considerably from system to system and center to center. As reported by Kisker et al. (1991) and Willer et al. (1991), the quality of care tends to be good in Head Start and centers based in public schools, and in contrast, weaker in centers run by for-profit child care chains. Child care quality varies significantly across family day care homes as well, tending to be better in regulated than in unregulated family day care homes (Gormley, 1995). In evaluating and selecting a program, parents ultimately make decisions based upon a variety of factors including child/staff ratio, provider training and education, child-centeredness, group size, provider turnover, physical environment, etc. These considerations may be secondary for parents of children with disabilities because the availability and affordability factors are so powerful and dominant. Alternatively, parents may believe that the unique needs of their child are best met by a family member.

Other frequently utilized services reported by parents were child focused and included WIC, child therapy, health care services, and community based socialization opportunities. This finding was substantiated in interviews conducted with select families in this study (McWilliam, Tocci, and Harbin, 1995). Thirty-four percent of the families elected to purchase additional child therapy that was above and beyond what they received in early intervention. Several explanations may be offered. Parents may seek supplementary therapy presuming that "more" is better, because of a perceived void or limitation in the services provided by early intervention, or to achieve a specific, valued goal, such as walking. This may explain the relatively frequent use of additional physical therapy for infants and toddlers. The influence of pediatricians may be a factor here as well since the medical community commonly recommends physical therapy for young children with disabilities.

Services which were available to meet specific parental needs (e.g., education, employment, housing, counseling, etc.) were used infrequently by families of infants/toddlers enrolled in early intervention programs. Whether this reflects a low level of need for these services, an emphasis on meeting child rather than personal needs, or a lack of support for addressing these needs is unclear from available data.

For the preschool sample, again, the majority of families accessed resources and supports while participating in programs. Services accessed were more often child-centered, including child therapy and child care services. The rate with which preschool parents utilized child care services was approximately equal to that observed among families with infants/toddlers in early intervention. Fifty percent of parents of preschool children accessed child care/preschool services whereas 55% of parents of infants/toddlers did so. Of interest was that families of

infants/toddlers and preschool children were similar in that they preferred child care by a family member or friend as opposed to more formal child care options.

Frequent utilization of supplementary child therapy is of considerable interest, particularly since a child's needs are, in theory, fully addressed within the preschool program. Speech and language therapy was the most highly utilized service among all categories for preschool children, suggesting that language development and school readiness are of high priority and/or need in contrast to other child/family needs. Recent research indicates that the pursuit of individual therapy services is "relentless" and "widespread" (McWilliam, Lang, Vandiviere, Angell, Collins, and Underdown, 1995). Their surveys and interviews with families suggest that alternatives to individual therapy are perceived as inferior and inadequate by parents. Parents believe that frequent direct therapy will bring the most results and, when the early childhood system does not provide as much therapy as parents want, parents elect to pay for costly private therapy themselves or with their insurance.

Finally, parents of preschool age children accessed informal social supports equal to families with infants/toddlers. Twenty-six percent of the preschool sample utilized recreation/socialization services at least one time during the sixteen month period while 24% of families with infants/toddlers did so during a three month period. While this difference may be simply explained by the age, needs, and abilities of children at different stages of development (birth to three years vs. three to five years), it may also reflect increased willingness of parents to venture into neighborhood social support systems with a preschool age child with special needs. These findings may also imply that communities are now more accepting of inclusion and integration of children with special needs. It would appear that early childhood programs have

succeeded in helping families access the resources and supports within their immediate neighborhoods.

It is also significant to note that the variability observed in community resource utilization among study states suggests that the influence of community context is strong. Social and contextual characteristics of each community likely influence the availability and utilization of child/family resources, and this is an area that requires additional inquiry.

While findings reported in this paper are thought-provoking and encouraging, many questions remain unanswered. Moreover, since the programs in this study were perceived as exemplary, these findings may not accurately reflect the status of early intervention and preschool nationally. In addition, the findings may not reflect community resource utilization for those socioeconomic groups (i.e., moderate to high) under-represented in the sample.

Overall, it would appear that families with young children with disabilities have become engaged with a myriad of resources beyond those offered by formal programs. Attempting to understand how, why, by whom, and when these resources are used all constitute important avenues of further inquiry. Additionally, understanding resource utilization patterns for children and families over time is also imperative. Findings in this study suggest that communities and neighborhoods are becoming a significant part of the early childhood experience, and future descriptive and outcome studies will need to account for this broader universe of resources and services that families with young children with disabilities have rightfully gained access to.

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Appendix A

Infant/Toddler Resources and Supports Protocol

E.C.R.I. Early Childhood Research Institute

Child and Family Resources and Supports Protocol

Child's Name _____ (Last / First / MI)

County _____ State _____ Week Ending Date (Saturday) _____ (Mo. Day Year)

Care Manager Name _____ (Last / First / MI)

Child and Family Resources and Supports Used

Please indicate those resources and services that were used by the child and family during the week reported. Include all resources used even if they are not included within the IFSP. If no services were used for the week reported, write N/A across the face of the sheet. Follow the same instructions for the back of this form.

	Child Resources/Supports Used	Have used during the week reported.
1	Family day care (licensed)	
2	Center based day care (licensed)	
3	Child care by a family member, friend, or neighbor	
4	Parent Child Center	
5	Family Center	
6	Speech/Language therapist	
7	Physical therapist	
8	Occupational therapist	
9	Psychologist	
10	Home health care services	
11	Neighborhood play group (formal or informal)	
12	Recreational programs (e.g., swimming or gymnastic classes)	
13	Other social/learning activities (e.g., library story hours, church groups)	

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	Family Resources/Supports Used	Have used during the week reported.
15	Housing	
16	Transportation	
17	Clothing	
18	Phone Service	
19	Emergency Fuel Program	
20	Food/Adequate Nutrition	
21	WIC (Women, Infants, and Children Program)	
22	Employment for Parents	
23	Parent Education Program	
24	Additional Education for Parents (GED; College Degree)	
25	Vocational Training/Rehabilitation for Parents	
26	Financial Counseling	
27	Legal Assistance Services	
28	Respite Care	
29	Homemaking Services	
30	Health Insurance	
31	Primary Health Care Services	
32	Medical Specialty Services	
33	Home Health Care Services	
34	Mental Health Services	
35	Substance Abuse Treatment	
36	Self-Help Groups (e.g. for substance abuse, weight reduction)	
37	Enhanced Informal Social Support System	
38	Information on Community Based Resources	
39	Opportunities for Socialization with Other Adults & Families	
40	Recreational Opportunities	
41	Other_____	

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Appendix B

Preschool Resources and Supports Protocol

E.C.R.I. Early Childhood Research Institute

Preschool Weekly Service Summary

Child's Name _____ (Last / First / MI)

County _____ State _____ Week Ending Date (Saturday) _____ (Mo. Day Year)

Teacher's Name _____ (Last / First / MI)

	Service Type	Service Location Code	Provider Code and Last Name	Total hrs/week* (Round to nearest 1/2 hr)	Cancellation Code
1	Assessment				
2	IEP Meeting				
3	Service Coordination/Management				
4	Child Therapy				
5	Family/Child Therapy				
6	Family Counseling				
7	Transition Planning				
8	Consultation to Child Care Program				
9	Consultation to Other Agency				
10	Child Developmental Group				
11	Parent Education/Support Group				

Provider Codes

1. Adaptive PE
2. Audiologist
3. Educator
4. Nurse
5. OT
6. PT
7. Physician
8. Psychologist
9. Social Worker
10. Special Educator
11. Speech/Language Therapist
12. Vision Impairment Specialist
13. Hearing Impairment Specialist
14. Paraprofessional/Aide
15. Interpreter
16. Child Care/Head Start Teacher
99. Other_____

Service Location

1. Public School
2. Private/Non Profit Early Childhood Center
3. Head Start
4. Day Care Center
5. Nursery School
6. Family Center
7. Home
9. Other_____

Cancellation Code

1. No Show
2. Provider/Agency Cancellation
3. Client Cancellation

** Please place an asterisk next to those individual services (e.g., child therapy) that are provided in the context of a group activity.*

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Other Resources and Services

Please indicate those resources and services that were used by the child during the week reported. Include all resources used even if they are **not** included in the IEP. With regard to expenditures, please report the approximate amount of funds that were spent on each resource. "Preschool Funds" include all monies awarded to the school district and under the direct management of school personnel. Examples include city/town/county funds derived from property taxes, state aid to education, Chapter 1 funds, and Section 619 (IDEA) funds. "Other Funds" include special projects with limited term funding, Medicaid, insurance carriers, foundations and charitable contributions (e.g., United Way), other state or county programs, and direct parent expenditures.

	Preschool Funds Expended	Other Funds Expended
Family day care (licensed)		
Center based day care (licensed)		
Child care by a family member, friend, or neighbor		
Nursery school		
Family Center		
Head Start		
Speech/ Language therapist		
Physical therapist		
Occupational therapist		
Psychologist		
Home health care services		
Neighborhood play group (formal or informal)		
Recreational programs (e.g., swimming or gymnastic classes)		
Other social/ learning activities (e.g., library story hours, church groups)		
Other services_____		

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